

WHAT TEACHERS NEED TO KNOW ABOUT LYME DISEASE

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ABSTRACT

Although widely misunderstood, Lyme disease is the most prevalent vector borne disease in the United States. Children are the most at-risk group for Lyme disease, which can impact every system in the body. It can produce the musculo-skeletal, neurologic, psychiatric, ophthalmologic, and cardiac symptoms. The symptoms of Lyme disease can have a large impact on school performance. This article will enable teachers to recognize and appropriately support children with Lyme disease.

Lyme disease is a multi-system illness caused by the tick-borne spirochete *Borrelia burgdorferi* generally transmitted to humans from rodents through the bite of a tick. Lyme disease is the most prevalent vector borne disease in the United States and is found in every state (Brown, Redecha, & Christian, 1990; Center for Disease Control [CDC], 2007; Tager et al., 2001). Children are at high risk for Bb infection because they spend a great deal of time outside in areas where ticks live (CDC; Tager et al.). Lyme disease manifests a wide variety of symptoms that impact school performance. It is important for teachers and other school personnel to be familiar with Lyme disease to help support the children and families who are affected.

TRANSMISSION AND PREVENTION

Lyme disease is caused by the spirochete *Borrelia burgdorferi*, which lives in mice, squirrels, and other small animals. The bacteria is transmitted between these animals and to humans through the bite of an *Ixodes scapularis* or *Ixodes pacificus*, commonly known as a deer ticks. The adult ticks feed on the blood of deer. Deer do not carry or transmit the disease themselves; they are just the primary food source for the ticks. Young deer ticks feed on rodents and other small animals, which are carriers of the disease. Ticks are transmitted to

humans via contact with animals or vegetation where ticks are living. When the tick attaches to feed it spreads the disease to humans (CDC, 2009a).

Lyme disease usually occurs in summer or early fall when people spend the most time outdoors in the areas ticks live. The best method of protection against tick-borne illness is to avoid exposure to ticks. Ticks prefer cool, moist environments like high grass and leafy underbrush. To reduce the risk of tick bite the Center for Disease Control (CDC) recommends avoiding high-risk areas, wearing long socks, sleeves and pants, and the use of repellent with 20-30% DEET on exposed skin. The CDC strongly recommends checking frequently for ticks and removing any tick found promptly with fine-tipped tweezers. It is very important to monitor the health of the child after any tick exposure (CDC, 2009b).

Children spend a great deal of time outdoors in areas where ticks live. The incidence of new cases of Lyme disease is highest in children between the ages of 5 and 19 (CDC, 2004). Teachers and other school personnel spend a large amount of time with children and may be able to notice new symptoms.

HOW LYME DISEASE AFFECTS CHILDREN

Lyme disease has three stages: early-localized, early-disseminated, and late (Beers, 2006). The first sign of infection is usually a circular rash called erythema migrans or commonly referred to as a bulls-eye rash. The rash is circular with a red rim. Estimates of the occurrence of this rash vary widely from 50-75% of people with diagnosed Lyme disease (Feder, 2000). The rash is a definite sign of infection and requires prompt medical attention (CDC, 2009c). When the rash appears it begins at the site of a tick bite after a delay of 3-30 days. The rash may feel warm to the touch but does not hurt or itch. Many patients also develop flu-like symptoms of fatigue, chills, fever, headache, muscle and joint aches, and swollen lymph nodes. Early treatment with antibiotics is most effective in helping to prevent complications (Beers, 2006; CDC; Hamlen & Kilman, 2007).

Lack of effective early treatment of Lyme disease may lead to complications. Lyme disease can affect every system in the body including musculoskeletal, neurologic, psychiatric, ophthalmologic, and cardiac (CDC, 2009c; Donta, 2005; Tager et al., 2001). Although a child may present with a specific set of symptoms, diagnosis can be difficult because the symptoms may wax and wane or be sporadic in nature (Tager et al.).

Despite the public perception that focuses on arthritic symptoms, particularly in children, these symptoms are not universal. A review of records of 101 patients ranging in age from 2-19 years found a variety of symptoms.

The most prevalent symptoms were musculoskeletal (90%), fatigue (84%), headache (78%), cognitive dysfunction (74%), stomach pain or nausea (48%), paresthesia (46%), eye symptoms (40%), and fever or sweats (39%). A variety of other symptoms were found in 79% of pediatric patients. These symptoms included, but were not limited to, dizziness, heart palpitations, and tremors (Donta, 2005).

Many of the symptoms of Lyme disease impact school performance. The neurological and cognitive symptoms in children with Lyme disease may be extensive and varied (Tager et al., 2001). Many children display an inability to perform at grade level, they may have inconsistent or sloppy schoolwork, late assignments, dropping grades, or develop school phobia (Hamlen & Kilman, 2007). These children may appear fatigued, fall asleep in class, or have excessive absences. Although physical symptoms may also have a negative impact on school performance, by keeping children out of school or making it difficult for them to participate fully, the cognitive symptoms may be more detrimental. Children with Lyme disease may have deficits in memory, short-term, sequential, spatial, and tracking, or slowness in word retrieval. These problems can negatively impact all areas of learning and school performance (Hamlen & Kilman). Children with Lyme disease may also display executive function impairment and have an inability to activate or sustain effort and attention. They may have difficulty managing frustration, display confusion, and have difficulty expressing thoughts. Abnormal emotional and uncharacteristic behavioral presentation, withdrawal from peers, depersonalization (loss of sense of physical self), cessation of involvement in sports or other activities, inattentiveness, attention deficit behavior, obsessive compulsive behavior, depression, anxiety, panic, aggression, defiance, mood swings, irritability, nightmares, and sudden suicidal thoughts may also occur in children with Lyme disease (Hamlen & Kilman). The symptoms of Lyme disease are varied and may progress in any order. Symptoms may start and stop or vary in severity within one child and no two children are going to present exactly the same characteristics (Donta, 2005; Tager et al., 2001).

DIAGNOSTIC CONTROVERSY

There currently exist two standards of care for the diagnosis and treatment of Lyme disease. Although teachers will not be using the diagnostic criteria and are not part of the medical team that makes a diagnosis, they should be aware of the controversy that surrounds the illness. The corner stone of the current debate within the medical community regarding the diagnosis and treatment of Lyme disease is the lack of a definitive and readily available

laboratory test for active infection (Donta, 2002; Feder, 2000; Tylewska-Wierzbanska & Chmielewski, 2002).

The Center for Disease Control (CDC) criteria for Lyme disease exist for the purpose of monitoring the rate of Lyme disease nationally. The disease is narrowly defined in order to ensure a high degree of specificity in the diagnosis. These criteria are mainly useful for the early stages and rheumatologic presentations of Lyme disease, such as when a patient appears with an erythema migrans rash, arthritis, a Bell's palsy, or early central neurologic Lyme disease (meningitis or encephalitis) (CDC, 2009c).

The two standards of diagnosis and care are advocated by two different medical organizations. The Infectious Disease Society of America (IDSA) and the International Lyme and Associated Disease Society (ILADS), both have published diagnosis and treatment guidelines; these guidelines are vastly different from each other (Feder, 2000).

Doctors in the IDSA follow the criteria set forth by the CDC and use those criteria for diagnosis as well as surveillance. These guidelines are restrictive in that fewer patients would be diagnosed as having Lyme disease if a doctor follows them as compared to the ILADS guidelines. The IDSA advocates for using the current two tiered testing procedures (Feder, 2000; Stricker, Laurin, & Burrascano, 2005).

Many ILADS doctors feel the CDC criteria are not very helpful for the clinician in detecting all stages of Lyme disease. For example, the most common manifestation of late neurologic Lyme disease is cognitive dysfunction (often referred to as "encephalopathy"). A patient who presents with new onset encephalopathy and a positive blood test for Lyme disease would not be considered by the CDC to be a case of Lyme disease (Stricker et al., 2005). Although the CDC recognizes that Lyme encephalopathy exists, encephalopathy is not part of the surveillance case definition. Therefore, physicians who rely on the narrow surveillance case criteria of the CDC for clinical diagnosis will fail to diagnose some patients who in fact do have Lyme disease; in these cases, the patient's treatment will either not occur or be delayed. Such absence of or delay in treatment may result in an acute treatable illness becoming a chronic less responsive one. Other physicians who use a broader more inclusive set of clinical criteria for the diagnosis of Lyme disease will make the diagnosis of Lyme disease and initiate treatment. The latter group of doctors, by treating some patients for probable Lyme disease, will make use of antibiotic responsiveness to confirm their diagnostic impression (Stricker, et al., 2005). These physicians, by not letting a patient with probable Lyme disease go untreated; will help many patients who otherwise would not get treatment. However, because of the inclusiveness of their diagnostic approach, these physicians will also treat some patients with antibiotics who do not have Lyme

disease. These physicians would argue that the serious consequences for physical, cognitive, and functional disability associated with chronic Lyme disease outweigh the risks of antibiotic therapy.

Both sets of doctors are practicing medicine in a reasonable fashion based on the application of certain diagnostic principles, although the therapeutic approaches differ considerably stemming from the narrow versus broad criteria for diagnosis. This is the essence of the medical controversy surrounding chronic Lyme disease. A child may be in treatment with antibiotics for four weeks or until symptoms are gone, which may take years. Treatment depends on which guidelines the doctor follows. Until physicians have a test that definitively identifies the presence or absence of infection (and such a test does not yet exist), the controversy about the diagnosis and treatment of chronic Lyme disease will continue (Stricker et al., 2005).

IMPACT ON SCHOOL

Lyme disease may affect every aspect of a child's life. It is important for school personnel to know the potential impact of Lyme disease. School nurses and school psychologists have already been urged to learn more about Lyme disease (Hahn, Pinger, & Hahn, 1987; Hamlen & Kilman, 2007; Healy, 2000) due to their positions in the schools. Frequently symptoms develop in children who were previously healthy and who formerly performed well in the school environment. The symptoms of Lyme disease may mimic other disorders or illnesses. Lyme disease should be considered when unusual changes in behavior or academic performance are noted (Hamlen & Kilman; Tager et al., 2001). Teachers are in the position to note and monitor changes in school behavior. When symptoms negatively impact school performance the children may qualify for school-based services. Table 1 outlines a number of symptoms that may impact school performance.

SERVICES

Children with Lyme disease or other tick-borne illnesses may qualify for services under the Individuals with Disabilities Education Improvement Act of 2004 (IDEIA) as Other Health Impaired (OHI). Children served as OHI under IDEIA have:

Limited strength, vitality, or alertness due to chronic or acute health problems such as a heart condition, tuberculosis, rheumatic fever, nephritis, asthma, sickle cell anemia, hemophilia, epilepsy, lead poisoning, leukemia, or diabetes that adversely affects a child's educational performance. (U.S. Department of Education, 2009b).

Table 1.

Neurological and Cognitive Symptoms of Children with Lyme Disease.

Headache and stiff neck
Neuropathy (nerve pain) in back, legs, or hands
Paresthesia (tingling sensation), facial paralysis (Bell's palsy), tinnitus, and sensory hyperacusis (unusual sensitivity to sound or light)
Deficits in memory, short-term, sequential, spatial, and tracking, slowness in word retrieval
Decreased reading comprehension and handwriting skills
Impaired speech fluency, stuttering and slurred speech
Inability to perform previously mastered math calculations
Vision problems, difficulty seeing and following visually presented material, frequent blinking or tics, inability to coordinate eye movements, targeting difficulty
Musculoskeletal and coordination impairment, balance problems, clumsiness or vertigo
Executive function impairment, inability to activate or sustain effort and attention, difficulty managing frustration, confusion, and difficulty expressing thoughts
Frequent errors in speaking, writing, spelling, or dyslexic-like behaviors
Severe and chronic fatigue unrelieved by rest, falling asleep in class, frequent absence or tardiness
Emotional and uncharacteristic behavioral presentation, withdrawal from peers, depersonalization (loss of sense of physical self), cessation of involvement in sports or other activities, inattentiveness, attention deficit behavior, obsessive compulsive behavior, depression, anxiety, panic, aggression, defiance, mood swings, irritability, nightmares, and sudden suicidal thoughts
Inability to perform at grade level, inconsistent or sloppy school work, late assignments, dropping grades, school phobia

Adopted from Hamlen & Kilman, 2007

If a child does not meet the requirements of IDEIA the student may receive services under Section 504 of the Rehabilitation Act of 1973. To be protected under Section 504, a student must be determined to:

- 1) have a physical or mental impairment that substantially limits one or more major life activities; 2) have a record of such an impairment, or 3) be regarded as having such an impairment. Section 504 requires that school

districts provide a free and appropriate public education (FAPE) to qualified students in their jurisdictions who have a physical or mental impairment that substantially limits one or more major life activities. (U.S. Department of Education, 2009a).

School districts and parents can work together to decide which of these laws best serves the child. In either case an individualized plan, a 504 plan or and individualized education program (IEP), will be developed to ensure a successful school experience for the child.

POTENTIAL ACCOMMODATIONS

There are many potential accommodations for a student with Lyme disease. As with any other child receiving special education services the modifications should always be based on the individual needs of the student. The nature of Lyme disease requires that the accommodations and support be flexible and suit the changing needs of the child (Hamlen & Kilman, 2007).

IEP and 504 teams should consider the following accommodations: (1) Support level, increase the amount of personal assistance for a child. For example, assign a peer buddy or teaching assistant to the student with Lyme, or implement peer tutoring. Additionally, a teacher may have to check in more frequently about extended projects to make sure the child is still focused on the task. (2) Learning volume, adjust the number of items the student is expected to complete to the level of competency. For example, a teacher could reduce the number of social studies terms the student must learn at any one time or the number of math problems completed to show mastery of a concept. (3) Time, extend the amount of time the student is allowed for learning, task and project completion, and testing. (4) Instruction variety, the teacher adapts the methods by which instruction is delivered to the student with Lyme disease. This could be accomplished by using visual aids, providing more modeling or guided practice, offering hands-on activities, or using cooperative groups. (5) Skill level, adjust the skill level, problem type, or the rules on how the student may approach work. The teacher could allow the student to use a calculator, simplify task directions, and change rules to accommodate the student's specific needs. (6) Response, the teacher adapts to how the student responds to instruction. This includes allowing the student to respond verbally rather than in writing, letting the student show solutions, and granting the student the opportunity to use a scribe or assistive technology. (7) Participation, shorten the student's schedule, where necessary, by adapting the extent to which the student is actively involved in a task.

Teachers and educational teams should first and foremost focus on the needs of the child and family. Teachers monitor school behavior, note any

sudden changes, and bring this information to the attention of the parents and school level teams. When a child is ill and receiving treatment the teachers and school teams can provide for the individual needs of the student during the treatment by assessing the student and designing an individual plan to suit specific needs.

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